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# Investigating the Needs of Service Users with Co-occurring Neurodevelopmental and Mental Health Disorder

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## Project Title

Exploring the needs of service users with a co-existing mental health and neurodevelopmental disorder accessing Mental Health Services in Cwm Taf University Health Board (CTUHB)

## Introduction

Neurodevelopmental disorders are conditions which generally become evident in childhood, which are known to result in deficiencies in personal, social, academic and occupational functioning (American Psychiatric Association, 2013).

ASD is a common neurodevelopmental disorder (~1% of the population). To be diagnosed with ASD, individuals must experience difficulties with social communication and social interaction, and must also display restricted repetitive patterns of behaviour, interests or activities (American Psychiatric Association, 2013).

For this study, participants in Phase 1 will need to have been diagnosed with ASD and a co-occurring mental health disorder. However, it must be acknowledged that due to the high co-occurrence of neurodevelopmental disorders, most participants will have ASD and other neurodevelopmental disorder/s.

## Aims

1. To explore the needs of service users with co-occurring neurodevelopmental and mental health disorder, and to establish whether CTUHB are meeting these identified needs.
2. To evaluate knowledge and understanding of ASD amongst staff working within Adult Mental Health Services in CTUHB.

## Research Questions

### Phase 1:

1. What are the needs of service users with ASD and co-occurring mental health disorder accessing the Adult Mental Health Service, and are they being met by CTUHB?

### Phase 2:

2. What is the current level of knowledge and understanding of ASD amongst staff working within Adult Mental Health Services in CTUHB?

## Methodology

This project will be conducted in two phases; Phase 1 involves service users with co-existing ASD and mental health disorder, whilst the sample for Phase 2 is staff working within Adult Mental Health Services in CTUHB.

### Phase 1

Individuals with ASD and co-existing mental health disorder will take part in an online or face-to-face focus group/individual interview to explore service user needs and to establish whether these needs are being met by CTUHB's Mental Health Service.

### Phase 2

Mental Health Staff will complete a Knowledge and Understanding of Autism Spectrum Disorder Questionnaire.



Mental Health Staff will take part in a focus group exploring staff perceptions of their knowledge and understanding of ASD in relation to service user feedback from Phase 1.

## Inclusion Criteria – Phase 1

Service users must fulfil the following criteria to be eligible to take part in the study:

- be aged between 18 and 65 years
- be from within the West Wales and Valleys region
- have co-occurring ASD and mental health disorder
- have the capacity to consent
- be accessing services within the Cwm Taf University Health Board

## Inclusion Criteria – Phase 2

Mental Health staff can be seen to include (but not limited to): Psychologists, Psychiatrists, Physiotherapists, Occupational Therapists, Speech and Language Therapists, Nurses, Social Workers, Healthcare Support Workers and Students (from various courses).

Staff must be working in Adult Mental Health Services, including both inpatient and community mental health teams.

## Findings

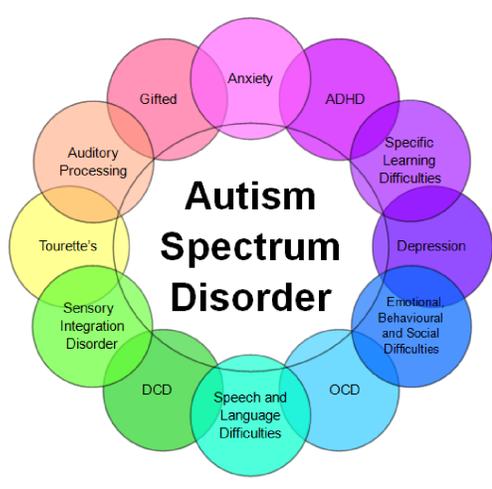
The needs of service users with co-occurring ASD and mental health disorder will be identified, and whether these needs are being met by CTUHB will be determined. The level of ASD knowledge of staff working within Adult Mental Health Services will be established.

## Potential Outcomes

A potential outcome from this study is the development of an effective service delivery model for adults with ASD and co-occurring mental health disorder who access the Adult Mental Health Service in CTUHB. This project allows for the voices of service users to be heard when evaluating the Mental Health Service, and for service users to be involved in developing the services they access.

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Participants with any co-occurring mental health disorder will be considered. However, it is anticipated that the most common found will be depressive and anxiety disorders. Depressive disorders are characterised by feelings of sadness and emptiness, and irritable mood which significantly impacts on an individual's ability to function, whilst anxiety disorders are disorders which are characterised by excessive fear and anxiety, which results in behavioural disturbances (American Psychiatric Association, 2013).

Co-occurrence between ASD and the above mentioned disorders is high, 42-56% for anxiety, and 12-70% for depression (Lai, Lombardo and Baron-Cohen, 2014). A study by Croen et al. (2015) demonstrated that adults with ASD have significantly increased rates of many psychiatric disorders including bipolar disorder, obsessive-compulsive disorder, schizophrenia, and suicide attempts compared to a neurotypical sample.

Therefore, it is important for the voices of people with ASD and co-occurring mental health disorder to be heard to help improve the Mental Health Service for this population.

**Phase 1:** Services users will be given the choice to take part in a focus group or individual interview, either online or face-to-face. The focus groups/interviews will take approximately one hour. The focus group questions have been devised specifically to answer the research question for Phase 1. Sixty service users will be recruited to take part, with access to participants being facilitated by CTUHB. Online focus groups/individual interviews will be undertaken on a programme called Blackboard Collaborate and the transcript saved, whilst face-to-face focus groups will be audio-recorded and transcribed.

**Phase 2:** Staff working within CTUHB's Adult Mental Health Service will be approached to complete a 'Knowledge and Understanding of Autism Spectrum Disorder' questionnaire. The questionnaire was developed for this study, based on three already existing questionnaires (Kuhn & Carter, 2006, Bauer et al., 2015 & Hansen 2015). Staff will also be given the opportunity to take part in an optional follow-up focus group.

